Department of Mental Health (DMH)
Mental Health Services Act (MHSA)
Stakeholder Input Process

PERFORMANCE MEASUREMENT AND INFORMATION TECHNOLOGY (IT) WORKGROUP

JUNE 23, 2005 – SACRAMENTO

Meeting Summary

For Discussion Only

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I. Background

The Mental Health Services Act (MHSA) became state law on January 1, 2005. The passage of the Act has created the expectation of a comprehensive planning process within the public mental health system. The multiple components of the MHSA are designed to support one another in leading to a transformed culturally competent mental health system. This is reflected in the California Department of Mental Health's (DMH) *Vision Statement and Guiding Principles for DMH Implementation of the Mental Health Services Act* of February 16, 2005: "As a designated partner in this critical and historic undertaking, the California Department of Mental Health will dedicate its resources and energies to work with stakeholders to create a state-of-the-art, culturally competent system that promotes recovery/wellness for adults and older adults with severe mental illness and resiliency for children with serious emotional disorders and their families. In its implementation responsibilities under the MHSA, DMH pledges to look beyond "business as usual" to help build a system where access will be easier, services are more effective, out-of-home and institutional care are reduced and stigma toward those with severe mental illness or serious emotional disturbance no longer exists."

This series of three workgroup meetings addresses performance measurement. The first meeting, held on May 4, focused on the conceptual design of performance measurement. This second meeting, held on June 23, focused on developing performance indicators and the role of information technology (IT), and the final workgroup in the series will be held on September 19, 2005.

A client and family member (CFM) pre-meeting, held from 9:30 – 11:30 a.m., provided an opportunity for clients and family members to discuss the afternoon workgroup session purpose, review the workgroup agenda, provide feedback and network with each other. The afternoon workgroup was held from 1:00 – 4:00 p.m.

Forty-two (42) people attended the combined Performance Measurement and IT and Capital Facilities morning CFM pre-meeting and 96 people attended the afternoon workgroup meeting on Performance Measurement and IT. The summary for the Capital Facilities workgroup, held at the same time and place, can be found on the DMH website.

A. Meeting Purpose

The outcomes of the workgroup meeting were:

1. To prioritize outcomes and performance measurement areas
2. To map desired client and community outcome indicators and mental health performance indicators
3. To describe potential methods of measurement
4. To learn about how information technology will fit into performance measurement

B. Schedule of Meetings

All scheduled workgroup meetings in July have been postponed until the fall. DMH has posted the new dates on its website.

II. Client and Family Member Pre-Meeting (9:30 – 11:30 a.m.)

Forty-two (42) people attended the morning CFM pre-meeting, which was a shared meeting with the concurrent Capital Facilities workgroup.

A. Welcome, Introductions and Purpose of Today's Meetings

Bobbie Wunsch, Pacific Health Consulting Group (PHCG) and facilitator of the MHSA stakeholder process, introduced the client and family member session. She then introduced DMH staff and consultants who would make presentations at the afternoon workgroup: Stephanie Oprendek, Ph.D., Chief, DMH's Performance Outcomes and Quality Indicators Section, who is responsible for designing the performance measures to be used by counties and Gary Renslo, Chief of Information Technology for DMH.

Ms. Wunsch reviewed the agenda for the afternoon workgroup meeting.

Client and Family Member Questions and Comments

- Please do not have workgroup meetings on capital facilities that overlap with IT or other topics. There are only a few clients who can provide expertise on these specific topics.
- For clients and family members traveling long distances, it is important to be able to have access to complete information on all of the topics. Do not overlap meetings.
- If it is necessary to overlap meetings, cancel the CFM pre-meeting and hold one workgroup in the morning and one in the afternoon. It is more important for clients and families to be able to hear everything than to have the pre-meeting.
    - **Pacific Health Consulting Group Response (PHCG):** This is important feedback. This concurrent scheduling was an attempt to address several different topics as quickly as possible. Many topics originally scheduled for July have been postponed to the fall. The new schedule will be posted on the DMH website.

Dr. Stephanie Oprendek then provided a brief overview of the content and process for the afternoon workgroup meeting, including the many purposes for which IT is used in mental health. The workgroup meeting will provide DMH's vision for IT, which has electronic health records (EHR) at its core. There will also be a brief introduction to Extensible Markup Language (XML), the computer language that is the basis for distributing system standards and interoperability. The rest of the meeting will be devoted to seeking input on priorities for performance measures and to answer questions about IT.

Gary Renslo stated that his staff, DMH's IT experts, will be available to answer technical questions about IT in the afternoon session. There will be substantial time for questions about IT issues. DMH staff and consultants included Frank Biondo, DMH lead on MHSA IT and consultants Kayvan Kazeminejad and Tanya Rhodes, technical experts on XML.

B. Key Issues on Performance Measurement and IT

The next part of the CFM meeting was comprised of three small group discussions on performance measurement, IT and capital facilities. Each small discussion group first responded to one or two questions and then asked questions of the subject matter experts. The structure and timing of this process allowed for each participant to attend two of the three small discussion groups. The summary that follows combines the two small discussion groups' questions and feedback for each topic. The questions for Performance Measurement and IT were:

- *B.1. What are your suggestions for outcomes measures and indicators for the concepts of wellness, recovery, resilience and hope by age group?*

- *B.2. What are your ideas about how clients and family members can provide input on the development of IT systems and applications at the local and state levels?*

- *B.3. What are your suggestions on how clients and family members' confidentiality can be protected in the IT system? Can you suggest ways that county staff can effectively explain to clients and family members how confidentiality is protected?*

B.1. What are your suggestions for outcomes measures and indicators for the concepts of wellness, recovery, resilience and hope by age group?

Specific Measures

- Performance measures should be non-biased and culturally competent.
- Use the Substance Abuse and Mental Health Services Administration's (SAMHSA) Self-Direction Education Project performance measures with self-reports:
  - Freedom to decide how to live one's life that maximizes one's goals
  - Authority to control the dollars to purchase services
  - Support to make informed decisions about services and supports to achieve one's goals
  - Responsibility to achieve one's goals
  - Participation of people with mental illness in the design and implementation of the programs that support people to reach goals, including both peer-run and other services
- In terms of authority and responsibility over how money is spent to purchase services, people in conservatorships should have authority over money spent on their services.
- Empowerment
- When people do not have a job, they have low self-esteem. Therefore, employment would help in many aspects of a client's life.

- Self-advocacy, measured by self-reports and evidence from the outside
- Use an evidence-based survey that has been validated with self-reports.
- Measure effects of anti-stigma campaigns.
- Create measures for people who do not think they are mentally ill to help them meet society's expectations and laws and stay out of jail.
- Devise ways to assess how successful programs are in preventing or reducing incarceration in jails and prisons.
- Measure progression of housing situations toward clients' goals so that clients are not left to languish in board and care facilities.
- There must be indicators of programs and of clients themselves.
- Develop measures for staff performance, which can be answered by clients.

Education

- Providing adequate education about wellness and recovery is crucial. To measure recovery accurately, clients and family members must be familiar with and understand the concepts. If a person has never had hope, how can s/he identify improvement? If family members do not know what resilience is, how can they tell if their child is gaining it?
- Peer-run organizations that have been providing services for quite awhile must be able to document their organization's effectiveness and success. In order to meet MHSA and county accountability requirements, these organizations will need more education and training on accountability issues.
- Use shared terminology that is consistent across counties and age groups. At the same time, it is important to use agreed-upon age-appropriate measurements for each age group.
- Shared terminology can be client-generated and must be client-friendly.

Changes Needed: More Client-Centered Focus

- DMH must learn from past experience. Measures were used years ago for which self-report did not work well. Learn from that experience.
- The focus is wrong: the wrong people are measuring performance. Ask a client; do not ask a provider. For meaningful performance measurement, the client should be responsible for input and measurement.
- Hire clients and families to conduct client-designed surveys. That is the story that needs to be told.
- Clients need to have choice about what is done with the information gathered about them.

Track Progress Over Time

- Provide a snapshot of how a person's life is at different times. There used to be a tool developed at UCLA which showed exactly how a client was feeling about his life at a given point in time.
- The snapshot should be able to capture the effects of MHSA services on a person's ability to get a job, have a home, get work clothes, get a driver's license, get insurance, a power wheelchair, or attend a literacy program. The snapshot provides

a baseline and then measures the client's progress as s/he proceeds through wellness and recovery. It should start with the client's priorities.
- The snapshot should measure how the client feels, how s/he is progressing toward wellness and his or her goals. A scale should measure where a person is at each point.

Age Groups
- It is important to clarify what age group a measure is for
- Many measures can be for any age
- Self-advocacy taught to children and implemented as they age, for transition-age youth and for adults

Mental Health Planning Council
- The Mental Health Planning Council felt that the "meaningful use of time and capabilities" outcomes measure was unclear and vague and should be eliminated.
- The Mental Health Planning Council felt that a feeling of wellness and well-being is very important: all people want a sense of happiness, future and stability.
- The Mental Health Planning Council looked at what is currently available for measurement, rather than looking at what could be created.

Other
- Need diversity of leadership at the top and accountability.
- Conduct psychological evaluations of decision-makers.

Client and Family Member Questions on Performance Measures

Specific Measurement Questions
- Could indicators be measured by interviews, focus groups and surveys?
  - **DMH Response (Stephanie Oprendek (SO)):** Definitely. Many of the ideas discussed here fit into the framework. Interviews and focus groups are more time-consuming than surveys, but there will be special studies within the overall framework. These could be used as pilots for surveys. MHSA could also create its own wellness and recovery measures. However, DMH will also have to comply with federal mandates in terms of measurement of recovery.
- Is DMH evaluating the usefulness of the Recovery Oriented System Indicators (ROSI) survey?
  - **DMH Response (SO):** ROSI does not measure what many people are talking about measuring in terms of individual progress toward recovery. Nationally, performance measurement experts are looking at coupling ROSI with the Mental Health System Improvement Program (MHSIP) survey to evaluate the system's level of recovery orientation. DMH is looking toward SAMHSA for direction on this, which is important in terms of fulfilling requirements for federal block grant funding. At the same time, DMH is interested in measuring individual client recovery.
- What thought has been given to longitudinal studies and frequency of measurement, especially in terms of quality of life?

- **DMH Response (SO):** With the available technology, MHSA can conduct longitudinal studies according to multiple ranges of time. AB 34 tracks changes whenever they occur. Point-in-time studies resulted due to budget issues and the need to simplify methods. DMH is putting a lot of thought into how often measurements should be taken and recognizes that this will vary according to indicator.

- How does one measure soft quality of living issues in a binary system?
  - **DMH Response (SO):** Some measures lend themselves to coding, like a Likert scale. Some may require special studies that address more qualitative information. In some cases, DMH may start with a broad survey that will be followed with a special study to address specifics.
- How will DMH make this information understandable for consumers and family so that it will be usable?
  - **DMH Response (SO):** In the past, information has been disseminated with little or no context or explanation. DMH is operating with the philosophy that interpretation and usefulness of data are essential. The Department will also look at practical issues like coding within an EHR to make the information interpretable and useful within the context of services and supports received.

Individual Consumer and Family Member Issues

- Will information be available so that a clinician can see it whenever the client is seen? System-wide, it would be reasonable to have a long-term process, but clinical information should be available as soon as possible.
  - **DMH Response (SO):** Ideally, an EHR would be something clients, family members or others with appropriate, authorized access can enter information into. It would be able to track services or supports provided, how the client is feeling, with input from the case manager, client, family member, etc. It would provide information whenever the system encounters the client or family. Ideally, these measurements could be accessed by a service provider or clinician and the client in real-time so that they can be used to inform and improve services and positively impact recovery.
- It is important that the person completing a survey not be coerced in his or her responses: self-reporting measures are critical. The interviewer should not be someone who has a vested interest in the outcome of the survey. How will this be monitored or addressed?
  - **DMH Response (SO):** This has been a long-standing issue. DMH uses every means to ensure information is valid and confidential. Clinicians should be guided by their own professional ethics. Gathering information from multiple sources (clients, family members and others) in part mitigates this issue. It allows potential differences in perspective to be examined together to determine any discrepancies.
- Do the clients have access to their own information?
  - **CFM Response:** Rarely.
  - **DMH Response (SO):** Access is governed by current regulation, for example the Welfare and Institutions Code, HIPAA, etc.

County and State Issues

- Native communities are transforming the standard measures to use those applicable to their people. How tight will DMH's rules and regulations be for tribes? Will DMH be open to creative ways of measuring?
  - **DMH Response (SO):** MHSA must tell a statewide story. There will be a core set of measurements about most people and there could be measurements that are more detailed or pertain to special populations. DMH must find some way to measure core concerns across the State.
- Many counties have a lot of land and few people. As a result, many people experience isolation. Because of the small population size, these counties were given so little funding that some may be unable to conduct sufficient evaluation. The isolation means that follow-up must rely on individual efforts, because not enough surveys will be completed without that individual follow-up. Will there be a special pot of money to track individual people in small counties?
  - **DMH Response (SO):** Counties can use their CSS plan to document how they plan to use their funds for transportation and reaching underserved people in rural areas. Surveys and performance measures should go hand-in-hand with the services and supports that are provided. Evaluation should not be a separate process from services.
- How will MHSA implement performance measures at the county level?
  - **DMH Response (SO):** Performance measures will be developed statewide that all counties will need to adopt to tell the statewide story. DMH will also develop IT specifications for counties that support performance measurement data capture.
- Many of the reports handed to DMH are currently years old. At what point will DMH review the information and either provide technical assistance or insist on improvement? These data should be used to make positive changes.
  - **DMH Response (SO):** DMH is working to achieve real-time data that will arrive right away to enable much more efficient quality improvement. New technology affords that opportunity. There will be opportunity for fast reporting especially in terms of client needs.
- How will DMH solve the problem of incorrect reporting from counties? DMH should collect information from consumers and not depend on the county.
  - **DMH Response (SO):** DMH collects a lot of information from the client's perspective. Most of the information DMH will collect will be from the client's perspective. In terms of information that is inappropriately reported by counties, DMH can provide oversight and technical assistance. However, the trend is to obtain more and more information from clients. The DMH performance measurement paradigm addresses some of these issues.
- Since Medi-Cal does not recognize post traumatic stress disorder as a diagnosis, how can MHSA evaluate the effectiveness of services for it?
  - **DMH Response (SO):** If counties determine need for services and supports that are not Medi-Cal billable, counties may propose to use MHSA funds for those services and supports. MHSA funds and its evaluation are not limited to what Medi-Cal will pay for. The universe of needed services and supports may

exceed what is stipulated in Medicaid regulation and medical necessity diagnoses and other criteria.

- Why is DMH compiling the data? To help the drug companies push their drugs?
  - **DMH Response (SO):** Outcomes measurement data is compiled to demonstrate accountability by counties and the state. Drug companies are not currently involved in the performance measurement process.

Questions for Later Consideration

Participants submitted additional questions to be recorded for discussion at a later time.

- What are the guidelines for hiring for wellness: peer counselors vs. hiring licensed clinicians?
  - **DMH Response (SO):** The MHSA highlights recovery and counties are encouraged to develop plans that promote recovery through the use of peer counselors and other client-centered strategies.
- Do more work in determining performance measures with tribal groups and other ethnic groups.

<u>Information Technology</u>

B.2. What are your ideas about how clients and family members can provide input on the development of IT systems and applications at the local and state levels?

System Requirements

- Appointment scheduling
- Prescription refills
- Access to providers and clinicians
- Instant response to crises (60-90 seconds)
- System should enable medical record annotation and error correction
- Americans with Disabilities Act (ADA) accessibility: technology needs to be adapted for clients and staff who are vision impaired, as well as other disabilities and literacy levels, including learning disabilities
- There is concern that none of the issues listed here is in the materials, but that the IT proposal is focused on infrastructure

IT Goals and Vision

- Be guided by evidence-based practice: greater access capacity should mean more data to determine what works
- Technology should enable policy choices, not limit them, as has been the case
- Aim for a fully digitized system and start by touring places where such systems have worked. The Veteran's Administration (VA) has done this and perhaps could provide training and help MHSA build on their success.
- Be guided by a focus on what can be done with data and files, not on what cannot be done, which is currently the emphasis

Insufficient Client and Family Member Focus

- Focus of the paper is on the system, not on the clients and person; start with user
- Families have been left out. Many of the comments apply to family members who need input.
- Clients and family members should be represented on development teams to maintain perspective as systems are being designed. Invite representatives from different client and family member groups in order to get different perspectives.
- Paper surveys are technology too.
    - **DMH Response (Gary Renslo (GR)):** The current technology plan focuses on a short-term and a long-term vision that will result in a technology infrastructure to support the MHSA accountability requirements. This infrastructure will also be the foundation for detailed requirements that are critical to clients and family members.
    - **DMH Response (Carol Hood (CH)):** Two levels are being discussed and it is important to clarify which goal is intended for the IT stream of funding. At the county system level, IT refers to the resources used to do what MHSA is intended to do. Increasing client access is a very important goal, but not one that has been discussed for IT funding.
    - **CFM Response:** It is not acceptable to separate IT from client access; it should not be a stand-alone. What is needed is to start with users and determine the type of infrastructure needed to support their involvement. The current IT system is broken and needs to be re-thought and re-designed. Information belongs to the client. MHSA is at risk of spending a lot of money making a bad thing worse. Priority is supposed to be the clients, not the system.

Client Evaluations

- DMH is at risk of creating a technical system that provides the same kind of unhelpful information currently used. Statistics-gathering methods of DMH reflect a problematic process and enable conflicts of interest to impede authentic evaluation: clients come in, service providers write down what they think they did and there is no opportunity for clients to evaluate services. Clients should be able to report on what they wanted and what they got and those data should be captured. Information will be more accurate and transformative. Surveys are critical, but they need to by-pass providers, in order to enable clients to communicate grievances and suggestions, or to have surveys conducted by consumer staff.
- Clients need to be involved and technology platforms should be developed to meet their needs (e.g., clients develop a survey and DMH provides technology to implement). Technology can be used to solve logistical problems of getting insufficient input; the technology must work for clients. Clients can receive training to complete surveys in different places: advocacy groups, housing, libraries, public places, etc. San Diego has a project with almost 1,000 surveys.
- Performance evaluation is vulnerable to manipulation. It is critical that the perspective of providers and the pharmaceutical community is balanced by client input and peer review. Transparency is really critical.

- Develop a “café system” in which the client decides what s/he wants and evaluates what s/he is getting.
- There should be a quality assessment group, not to control, but to provide feedback and evaluate, with clients and family member participants.

Consumer Access to Records

- Access to records should not be dependent on provider. Clients themselves, or their designees, should be able to access records on demand.
- In the Village program, every consumer has access to his or her own file.
- Some counties have a Network of Care, but current discussions focus on the Network going statewide. Is there a chance of integrating, so that clients can communicate with the system? IT should be talking with Afshin Khosravi (Trilogy Integrated Resources) about “My Folder” process, and partner in development of Network of Care.
    - **DMH Response (GR):** DMH is supporting the Network of Care statewide expansion and will explore the best uses of the system.

General Access Issues

- All service delivery sites should enable access to public computers and the Internet.
- Literacy level is a problem for access to computers in public places.
- Literacy accessibility is critical: programs should do voice output and input.
- 800 number for consumers to call with concerns any time about anything related to their mental health.
- Isolation and access issues need to be addressed in order to bridge the IT gap and span geography and other types of isolation. All clients need to have access and give input.
- Colusa County has a partnership with county and schools on surplus technology for dissemination of donated machines. More staff are needed to clean drives and train users.
    - **DMH Comment (Tanya Rhodes (TR)):** There are many programs like this. DELL has a program to clean drives and re-load basic programs.
- Access to internet
- E-mail access for peer support
- All housing should be broadband-wired

Cultural Competence

- IT must be culturally competent. There is a problem for Hmong and other languages using standard keyboards. Public access terminals make this challenging. Touch screens may be the only solution.
- Linguistic access would be enhanced through use of touch screen menus that eliminate the need for the keyboard, as well as the language on the screen. Systems for providers and consumers must be available in multiple languages.
- Culturally sensitive translations are impossible when translations are being done by computers, not people.

Training and Support

- Clients need one-on-one help to understand the importance of confidentiality and need training regarding who to share what with. The biggest protector is the person who holds the information.
- Simple communications are necessary to elicit intelligent comments from consumers and family members. Recognize that acronyms, systems, etc. are confusing.
- There needs to be an ability to send something instantly to IT concerning problems and needs. Access should be both web-based and available via phone. Strong technical support is required; it should not be difficult to access a Help Desk.
- Develop information kiosks that provide information regarding mental health services and client rights and answers, in layman's terms, to the question, "What does HIPAA mean to you?"
- Develop a call center. The best way to fund it would be to pay consumers for their data! It is their data but they have no control over it.
- Hire clients for technical support.
- Consider education and training with a focus on de-mystifying IT and giving people a sense of choices, possibilities and choices.
- There should be IT training across the board and to develop processes for peer and client review.

Alternative Models

- Approach IT from the perspective of Internet resources like Wikipedia.com (which is built on open source programming, knowledge-based resources) that can engage clients in broader ways than have been the case historically. This type of platform allows for two levels: 1) superficial level of public access to vast knowledge resources, to share information and do research; and 2) sub-surface level which could be accessed only by clients themselves to balance the providers' perspective. The existing system is dysfunctional: binary, impersonal, linear and de-contextualized.
- San Joaquin County is using a SmartCard system, which piggybacks on the DMH server and enables clients to refill prescriptions, schedule appointments and store all their information. This type of card can also be used to help clients bridge from conservatorship to regular banking and money management. One big problem is that clients cannot always remember their passwords. Providing a prompt for something like a pet's or relative's name helps. Card is authenticated along with password.
- Health, mental health and financial records should be kept separate. There should not be too much information on something like a SmartCard: all that information in one place is too much to lose.

County Processes

- In terms of developing interoperability, it would be helpful to see the cost differential for adapting vs. developing.
- What is the process for replacing the current system? What is the baseline? With INSYST sunsetting, there is a unique opportunity for change.

- How can consumers learn about the progress counties are making in their planning processes? It would be great to have the minutes from county meetings posted on the web to improve communication.
- Small counties and programs already have software in place. The new vendor will need to know what DMH will require. Small counties and programs are making blind decisions, since the system is still in the planning stages.
    - **DMH Response (GR):** A coalition of small counties has looked at these issues and how they apply to small counties. The long-term plan will not be done immediately. A transition will occur over the next few years. DMH will survey vendors and obtain input, and will look at a variety of systems and capabilities.

B.3. What are your suggestions on how clients' and family members' confidentiality can be protected in the IT system? Can you suggest ways that county staff can effectively explain to clients and family members how confidentiality is protected?

Trust Issues

- It is important to recognize that there is a diversity of opinion: on one hand, clients want full access to all their own information as needed, but also want it protected like Fort Knox.
- What about issues of confidentiality for family members vs. clients?
- Confidentiality for most clients is a trust issue: most clients think that confidentiality is a joke. If DMH institutes transparency, so clients can more easily see who knows what, it might improve this.
- The system has to be built to meet client needs, be responsive and maintain confidentiality. Clients may not always know the provider, or what the process is for every transaction. Sometimes the person who needs to know might change at the spur of the moment.
- Many consumers have illnesses that do not allow them to trust or to protect themselves. Clients need extra safeguards, especially with greater emphasis on clients in workplace.

Security Issues

- More honest conversation about security and confidentiality is needed. Systems for how DMH will deal with hackers and invasions must be developed. All systems are vulnerable. It is important to be up front and honest about this.
- When talking about client accessibility and the system, consider confidentiality. When a person logs in, how will the system know who is accessing it? What are the safeguards? Is it possible to use fingerprint ID and a two-tiered system for authentication, which adds a password (6-8 digits, using NSA standards) to the fingerprint ID?
    - **DMH Response (GR):** DMH has been looking at fingerprint technology. IBM has new fingerprint swipe technology that is harder to break.
- There should be a capacity to set the security level in terms of who has access to what information. Clients need control over their own information. For instance, a

client might restrict employee access to medical records, but enable full access for emergency room admissions.

- There should be tiered access: general information at a lower level of security and then personal financial, legal, and medical information at a more secure and restricted level.
- It is problematic for client advocates, working in agencies, when staff have access to their personal charts. Any proper name contained in charts should be blocked from view for people doing any reviews.

Permission

- No one should get access to data without permission.
- Permission for each exchange is a challenge to portability. So many transactions go on in a day that this kind of process is just not feasible.
- County health departments do authorization and review with free-flowing charts. Authorization and utilization personnel do not need to see names. On the other hand, firewalls should not be so inflexible that it becomes difficult to access records. The bottom line is that information should only be available on a strict need-to-know basis, especially when it comes to any information that can connect a client's name to a file.
    - **DMH Response (Kayvan Kazeminejad (KK)):** DMH can establish unique identifying information in order to access confidential information without mapping on to particular client name. Technically everything mentioned can be done by enabling a process that changes the point-of-view on the record depending on who is looking at it. That way different information is available for prescriptions, for financial decisions, etc.

HIPAA

- Systems should already be providing a lot of these portability protections, according to Health Insurance Portability and Accountability Act (HIPAA) regulations and standards.
- The saddest thing is that confidentially is usually used as a way to say "no" to people: "Can't do that because of HIPAA." Staff, clients and family members need more education to understand what HIPAA is all about. HIPAA was intended to silo information.
- Many providers do not understand HIPAA.

Data Collection

- Be very strict about what information is captured: limit to information that is critically important.
- There are many risks inherent in centralizing information and it is really important to pay attention to accountability and risks of abuse.
- The national discussion invokes concerns about the Patriot Act and how much client information should be interlinked. On the other hand, integrating these streams and this information is inevitable.

III. Workgroup on Performance Measures (1:00 – 4:00 p.m.)

Ninety-six (96) people participated in the afternoon workgroup meeting.

A. Welcome, Introduction and Purpose of the Workgroup Meeting

Bobbie Wunsch, Pacific Health Consulting Group and facilitator of the MHSA stakeholder process, welcomed the participants. She announced that the July workgroup meetings would be postponed until the fall.

- **Stakeholder Question:** How many follow-up meetings will there be for performance measurement?
  - **PHCG Response:** This is the second in a series of three workgroups on performance measurement. There will be a second IT meeting on September 12, 2005, focusing primarily on financing and capital facilities, as well as a third meeting on performance measurement on September 19, 2005.

B. Performance Measurement and Information Technology

Stephanie Oprendek, Ph.D., Chief, Performance Measures and Quality Indicators Section, presented information from the PowerPoint presentation titled, *Information Technology Infrastructure for California Mental Health System Accountability Vision, Preliminary Concepts, Early Strategies: Integrating Data Project Silos and Increasing Performance Measurement Capacity through a Comprehensive Electronic Mental Health Technology Enterprise.*

Mental health information systems

The major purposes of these systems are:

- Electronic capture and distribution to improve services and mental health, such as electronic health records (EHR) and information access networks
- Resource management at the state level for appropriation, and at the county level to monitor funding streams, etc.
- Performance measurement and accountability: "Are we doing what we should do and what we said we would do?" and "Are we achieving what we set out to achieve?"

Main sources of accountability information currently used

- Local service encounter reporting systems: client and services information (CSI), including client identifiers, diagnosis, demographics, modes of services, service functions, providers, etc. This includes monthly reporting to state CSI, federal DIG/URS, Medi-Cal claiming, billing and cost reporting.

- DMH centralized client survey reporting system of client perception of service quality and outcomes. This includes online key entry, integrated local scanning of paper forms with central verification, and semi-annual reporting from local survey systems.
- Key event outcomes tracking system: ongoing collection of changes in objective quality of life (AB 2034 methods). This is a key-entry system that is separate from local service encounter systems.

There are a number of isolated processes or isolated data projects. The goal for IT within MHSA is to create an over-arching data capture system to streamline, integrate and coordinate business processes, technology and information.

Three areas of coordination and integration

1. Coordinate and integrate data
2. Create integrated and coordinated computer/communication technology systems through interoperability and make them user-friendly
3. Integrate resulting data for performance-based accountability by combining typically isolated data silos

Today's meeting focuses on the second of these areas: creating integrated and coordinated computer/communication technology systems. Dr. Oprendek emphasized the importance of adaptation, rather than adoption. Adaptation is an improvement in relationship to the environment and is consistent with the goals of MHSA. Once a fully interoperable electronic mental health information system (EMHIS) is created, the silos become part of the system, available for extracts and evaluation.

Gary Renslo, Chief of Information Technology for DMH, then presented the more technical aspects of the proposed EMHIS. He briefly described his ten-year experience working at DMH with the counties, first to build CSI, then addressing Y2K and HIPAA, and now with MHSA.

Ideal characteristics of the proposed EMHIS

- ***Flexibility:*** able to change data structures and requirements
- ***Extensibility:*** scalable for small and large counties with open system architecture allowing new features and functions to be added or plugged in at will
- ***Interoperability and Security:*** the system needs to operate and interface easily with other systems while information is protected for privacy at all times
- ***Responsiveness:*** the information should flow into the system as soon as it is gathered; business requirement changes must flow into the system as needed

Flexibility for meeting the business goals

XML (Extensible Markup Language) provides data flexibility: the goal is a self-describing data structure that does not depend on format, length or order. The XML data dictionary called SCHEMA can contain data relationships, business rules and translations. XML tools are available to assist in building and managing an XML-based system. XML is a robust industry standard.

Centralized definition and processes: automated tools are available to generate views and interfaces directly from published schema; changes to the schema can automatically generate new views of the information to the end user; and changes to schema will not require changes to applications.

Proposed phase strategy

Phase I, **short term strategies**: the current system is transformed to a new system that incorporates CSI, DIG and MHSA data, based on statewide standards and schema. There is likely to be a web form, which will be at least partially populated with data from CSI, and then DIG/URS and MHSA data can be added by the user.

DMH will provide a web-based application for data capture, with centralized schema-based web pages to allow secure, online entry for all new information; incorporate CSI, DIG and MHSA in system schema and applications; and provide submitted data back to the counties.

Phase II, **fully realized extensible system**: DMH will extend schema-based application, with enhancement of centralized schema-based web pages to allow entry online for all new system information; printable forms from the web will be available which can be scanned in to populate the web-based form; and counties or providers can build custom web-based forms using the provided XML schema.

DMH will build a schema-based information portal through which XML information can be sent from county or provider via secure file transfer protocols; plug-ins could be developed for county or vendor systems to access county files and extract and send information; and a staging database could be created where county information could be stored for access and processing.

The goal is for MHSA information to be available via an access portal. The following would be available: a web-based reporting and charting site, downloads of selected county or provider information, raw information returned directly to staging databases at the county level, and reports and analyzed information returned to county or vendor applications for access and processing at the county level.

Stakeholder Questions and Comments

Computer Access, Literacy and Disabilities

- What if a client does not have computer access? It is vital to reach rural communities to obtain their information.
  - **DMH Response (SO):** It is important to develop options for people who do not currently have computer access. Paper processes in some cases may need to continue. It is also important in California and across the nation that the issue of building inter-connectivity through a computer-based infrastructure is successfully addressed.
- One slide had value words. Please add to it "accessibility." This should encompass the ADA concerns of physical and learning disabilities, etc.
  - **DMH Response (GR):** This is not an all-encompassing list. It can be expanded, and accessibility is a good example.
- There are companies that have systems that work with the disabled, such as Intellitools. They have modified keyboards for people with dexterity issues, etc. These would work for a wide range of people.
  - **DMH Response (GR):** Accessibility is clearly a concern. DMH will work with the Department of Rehabilitation (DOR), which has addressed many accessibility concerns.
- Some clients are not computer literate. Keep things on paper as well for them.
- There should be translators for every type of disability, including people who are computer-illiterate. This would bring data into the system, create jobs, etc.
- Have voice-activation; it exists already. People could just talk to it, rather than rely on translator.
  - **DMH Response (SO):** DMH will head in the direction of using numerous technologies to meet the needs of persons with disabilities. Many details will need to be addressed as we move forward.

Confidentiality and Security

- How does this relate to HIPAA? Will DMH force people to disclose things they do not want to?
  - **DMH Response (GR):** Confidentiality is an issue. All systems are covered entities required to comply with HIPAA. DMH will look into conducting trainings on HIPAA to assist in understanding the compliance rules.
- How will DMH protect the system from break-ins?
  - **DMH Response (GR):** Obviously, break-ins can happen, but DMH has had no breaches so far. DMH's security infrastructure will be discussed more in the afternoon session.
- Data transfer is primarily aggregate totals.
  - **DMH Response (GR):** No, data transfers include specific individual records. DMH performs 14 million individual transactions every year with no breaches to-date.

Usefulness of Data

- Once DMH has these data and outcomes, will they be posted on the web transparently?
  - **DMH Response (SO):** DMH definitely wants to share the outcomes. It is essential that the data be useful for decision purposes. DMH is committed to disseminating information with explanations and context. Part of the role of the Performance Measurement Committee is to determine which will be the most useful. DMH will also work with the Mental Health Planning Council.
- Can clients input their own data, such as a log to mark their way to recovery? This sounds like it is all from medical records, rather than a means to measure self-esteem and recovery.
  - **DMH Response (SO):** DMH fully expects this client aspect to be included. The Department will start with a client survey. Imagine that as expanding more to incorporate more client input.

Trouble-Shooting

- In terms of XML: is it possible for data to get lost in the transfer?
  - **DMH Response (GR):** DMH is working on a handshaking protocol that assures the data are sent in their entirety.
- How will DMH address potential viruses within the data transfer?
  - **DMH Response (GR):** The data transmissions will occur over secured lines from source to destination, reducing the risk of viruses entering the transmission. The protection will also be enhanced with firewalls and virus protection software.

Timelines

- What is the timeline for Phase II?
  - **DMH Response (GR):** We are utilizing a concurrent development model. Counties should include similar short- and long-range timelines in their IT plans.
- What is the timeline for schema?
  - **DMH Response (GR):** This summer, over the next few months.

C. Ranking and Measuring Indicators and Outcomes

1. Summary of Client and Family Member Pre-Meeting Small Group Discussion on Performance Measurement

Sharon Kuehn, Contra Costa County Office of Empowerment, provided a brief summary of what had been discussed in the client and family member pre-meeting about performance measurement. Two small group discussions addressed the question below.

What are your suggestions for outcomes measures and indicators for the concepts of wellness, recovery, resilience and hope by age group?

Strong points were raised about how best to measure as well as the need to educate clients and family members about wellness, recovery, resilience and hope so they can

evaluate their own or their family members' progress in those terms. At the same time, both groups grappled with a lack of specificity for measures of empowerment, self-advocacy, happiness, stability, future, hope.

One suggestion was to use self-reports of outcomes from SAMHSA's Self-Direction Education Project, which include the following:

- Freedom to decide how to live one's life that maximizes one's goals
- Authority to control the dollars to purchase services
- Support to make informed decisions about services and supports to achieve one's goals
- Responsibility to achieve one's goals
- Participation of people with mental illness in the design and implementation of the programs that support people to reach goals, including both peer-run and other services

The importance of considering the needs of specific tribal groups and other populations was raised, as were the issues facing rural counties as they attempt to meet MHSA requirements. Finally, the centrality of clients in terms of choosing and evaluating their own services was affirmed.

2. Presentation on Performance Measurement and Performance Measurement Committee

Next, Stephanie Oprendek presented information from the PowerPoint presentation, *Measuring Specific Outcomes and Performance*. This information set the stage for the small group discussion to give feedback on outcomes and performance areas.

Demonstrating accountability involves measuring the effectiveness of services, supports and activities through individual client outcomes and community impact. It should be demonstrated that the mental health system is performing appropriately in providing services: that it is doing what it should do and what it said it should do.

All recommendations provided today will be forwarded to the Performance Measurement Committee. The committee will be comprised of approximately 20 people from throughout the State and will be representative of people interested in the mental health system. DMH will pay for travel expenses for client and family member participants; county representatives should use allocated MHSA funds.

Dr. Oprendek then introduced Dr. Tom Trabin, who will be the facilitator of the Performance Measurement Committee. Dr. Trabin has substantial experience in survey development efforts, has been an active leader in many areas of evaluation and performance measurement and has held both executive and clinical positions.

Dr. Trabin started by noting that because most of his work has been done at the national level, he is thrilled to translate this experience to his home state in the context of the MHSA. The national mental health community is watching how the MHSA unfolds, to see the results of extra money flowing into system. Many national leaders want to see if MHSA will translate into major policy changes in programs and real changes at the line level so that clients and family members experience transformation. They also want to know if these changes can be recorded so that policy makers can hear what has worked.

He then described the collaborative policy and performance measurement process. It begins with involving people in discussions in which people are listened to and they share their values. These values are divided into measurable domains. This is a challenging process to narrow down. Many perspectives are represented, with vocal advocates whose job it is to make their positions heard. There are trust issues in moving toward consensus. The degree to which the committee can build trust so they can move on to do the work, is important to the success of the process.

Consensus is arrived at with a few domains to measure. These domains need to be expanded into measures. The challenges for the development of these measures are that they have to be good measures, but they cannot be too complicated or burdensome. If they are, no one will want to implement them. It is important to ascertain who will be analyzing the data and implementing the feedback loop and how the information will be used. Too often, the people at the line level never hear back about the data collected. The data and analysis must be useful for accountability, so that the public and legislators can see success, and so that it can be fed back into the system for quality improvement.

Stakeholder Comments and Questions

Usefulness of Data

- These data must be understandable to the expected growing ranks of peer counselors. The average client or family member may become a provider, which requires that the information be very simple. It needs to be accessible to everyone.
  - **DMH Response (SO):** This is a very important point. DMH must make sure that people are educated about how to read the information and the data must be as clear as possible.
- One of the lessons learned from the State's and the Mental Health Planning Council's Quality Improvement Committees is that data must be seen in context. Information technology is a mechanical process, but the output must be understandable for everyone. It needs to be in a context so that it makes sense to the average person.
  - **DMH Response (SO):** DMH is committed to this.

Data Collection Burden

- How burdensome will it be for clients, clinicians and administrative staff to collect data in real time?

    - **DMH Response (SO):** With an EHR, it is possible to embed a substantial amount of outcome information into regular business processes of providing services and supports. Providing services and collecting information that can be used for performance measurement don't have to be disconnected or siloed processes. An EHR can therefore reduce the burden of data collection.
- Other providers and organizations will need the data to obtain other funding for their programs. For example, the Village has been gathering data for AB 2034 for years. It is not so burdensome.
    - **DMH Response (SO):** With limited resources, the amount of data that can be realistically collected is reduced. It is critical to collect data and show outcomes in order to obtain continued funding. Without data, programs cannot demonstrate accountability.

Interoperability

- Will DMH use data from other state agencies, such as the Department of Education (DOE) for school attendance?
    - **DMH Response (SO):** DMH is working with the Department of Health Services (DHS) and Department of Social Services (DSS). Some data linking is possible. DMH is also working with other departments to collaboratively design data fields and data collection processes. In some cases this could involve changing the ways agencies do business.
- A standardized form that incorporates multiple systems could get the same format from everyone involved. Everyone would be doing the same work, and it would be easy to map the progress.
    - **DMH Response (SO):** A lot of the discussion centers around developing a system or tool that is used by multiple agencies for the same clients. Achieving consensus across agencies can be challenging, but is becoming increasingly important as the positive effects of coordinated, inter-agency services delivery become more apparent.

Staff Issues

- Involve workers in designing the data collection measures.
- Make sure that line staff receive the feedback. Many staff are evaluated on specific outcomes. They need to be clear about what these are so they know how they are being measured.

Other

- There are at least two different ways to look at the concept. What is the priority for assuring that DMH can measure transformation in the system?
- A lot of items on Attachment 6 are very broad while others are very specific.

Dr. Oprendek then described SAMHSA's National Outcomes Measures Domains:

1. Abstinence
2. Employment/Education
3. Crime and Criminal Justice

4. Stability and Housing
5. Access and Capacity
6. Retention
7. Social Connectedness
8. Perceptions of Care
9. Cost Effectiveness
10. Use of Evidence Based Practices

She noted that DMH has to integrate federal reporting requirements to continue receiving federal funding.

3. Small Group Discussions on Performance Measurement

Ms. Wunsch described the process for small group discussion, using Attachments 6 and 7 of the paper, *Measuring Specific Outcomes and Performance Areas,* posted on the DMH website. Stakeholders were asked to select one age group for their participation. Participants were asked to identify the five or six highest priorities on Attachment 6, Column 2 and to identify at which levels (individual, system and/or community) they should be measured, on Attachment 6, Column 3.

After completing this, the groups were asked to identify and recommend how the top five or six outcome and performance areas might be measured on Attachment 7.

Attachments 6 and 7 are shown on pages 24 – 27. Preceding them is a brief summary of each small discussion group's primary diversions from the attachments.

Children and Youth

The group working on children and youth decided to revamp the exercise by identifying a framework of life domains that have emerged from child-serving system work over the past twenty years. The group noted that, ultimately, the specific outcome indicators selected need to be the result of listening to consumers, families and the community. *A fuller description of their recommendations follows Attachment 7.*

The Children and Youth group completed Attachment 6 by noting which domain each outcome or performance area related to, despite their reservations that the identified measures were not necessarily the best. They also eliminated the outcome measure of individualized service plan goals met, as they believed it was a process indicator.

The group identified four levels of mental health performance measurement: 1) the child and family; 2) programs; 3) system; and 4) community. As described currently by MHSA performance measurement documents, the program and system levels are combined.

Transition-Age Youth

The group working on transition-age youth made two changes to Attachment 6. They changed "safe housing" to "appropriate housing" and combined the two items addressing reduction in incarceration in jail and juvenile halls into "reduction in incarceration." In addition to identifying highest priorities, the transition-age youth group noted that timely access to needed help was a "higher" priority.

Adults

The two adult discussion groups had no overlap in their highest priorities, although one group identified reduction in homelessness while the other identified safe, adequate housing. The group which identified housing as one of its highest priorities wanted to combine "safe" and "adequate" into one outcome. One group also identified measures that should be tracked concerning the impact of pharmaceutical companies, in terms of the number of prescriptions written, drug company marketing, lobbying and profits, etc. This group identified additional outcomes for measurement: reduction in use of medications, self-advocacy, treatment with respect, and support to make informed choices. The group recommended changing "illness self-management" to "self-care" or "personal responsibility for wellness." The group further recommended eliminating "functioning" as one of the outcomes or performance areas.

Older Adults

The group working on older adults made a few changes in Attachment 6. The group modified "meaningful use of time and capabilities" to "meaningfulness/purpose in life, reduced isolation"; changed "reduction in institutionalization" to "reduction in unnecessary or inappropriate institutionalization (e.g., skilled nursing facilities (SNF), IMDs and acute inpatient)" and added "physical health" and "linkage to medical care." The group also added a number of additional outcomes related to older adults, including functioning, involvement with Adult Protective Services (APS), access to primary care, and reduction in conservatorships and guardianships. The group rated each of these additional areas as "higher" priorities, below the highest priorities marked by an asterisk.

Attachment 6 – Form 1: Priority Setting and Mapping of Outcome and Performance Areas

The participants divided into groups to address outcome and performance areas by age group (children and youth (C), transition-age youth (T), adults (A) and older adults (O)) and used the form below as their guide. Each age group noted their highest priority, which is shown as an asterisk (*) in Column 2 for each age group. The children and youth group, as described below, noted which quality of life domain each outcome measured: 1) health and well-being, 2) home, family and social network, 3) school, 4) out of trouble, and 5) safety.

After the small groups noted their highest priorities, they assessed what level of measurement the outcome should be measured at according to the MHSA performance measurement paradigm: individual client, mental health system or public/community impact (Column 3). The age group noting a level is shown by the letter associated with it in the chart.

After the outcomes and performance areas listed in Attachment 6 were discussed, the small discussion groups added new outcomes and performance areas they thought should be measured to Attachment 6, Column 1.

Column 1	**Column 2**				**Column 3**		
Outcome and Performance Areas *Please note: The Children and Youth group noted the domain relevant to each area. The domain numbers are identified below after Attachment 7. The letters in the Level of Measurement columns refer to the age group which listed it.*	**Age Group * = Highest Priority**				**Level of Measurement**		
	Children and Youth (C)	**Transition-Age Youth (T)**	**Adults (A)**	**Older Adults (O)**	**Individual Client**	**Mental Health System**	**Public /Community Impact**
Meaningful use of time and capabilities	3		*	*	O	A	
Employment	3	*	*		T, A	T, A	T, A
Vocational training	3						
Education	3	*					
Graduation rates for children / youth diagnosed with serious emotional disorders:							
Non-public school placement	3						
Social activities	4						
Community activities	4						
Network of supportive relationships	4 *	*	*	*	A, O		
Adequate housing	4		*		A	A	A
Safe housing	4	*	*		A	A	A
Safe living environments with family for children and youth	4 *				C	C	C
Reduction in homelessness	4		*		A	A	A
Reduction in out of home placements	4						
Child welfare status	1						
Reduction in incarceration in jails		*	*		A	A	A
Reduction in incarceration in juvenile halls	1, 5	*					
Reduction in involuntary services	2		*		A	A	

Column 1	Column 2				Column 3		
Outcome and Performance Areas *Please note: The Children and Youth group noted the domain relevant to each area. The domain numbers are identified below after Attachment 7. The letters in the Level of Measurement columns refer to the age group which listed it.*	**Age Group** *** = Highest Priority**				**Level of Measurement**		
	Children and Youth (C)	**Transition-Age Youth (T)**	**Adults (A)**	**Older Adults (O)**	**Individual Client**	**Mental Health System**	**Public /Community Impact**
Reduction in institutionalization	2, 4		*	*	A, O	A, O	
Hospitalization (long-term restrictive levels of care)	2, 4		*		A	A	
Hospitalization (acute)	2		*		A	A	
Timely access to needed help	2 *				C	C	C
Timely access to needed help in times of crisis	2						
Physical health	2		*	*	A, O	A, O	A, O
Symptoms/suffering	2						
Substance abuse	2		*	*	A, O	A, O	A
Suicide	2 *			*	C, O		O
Recovery	2		*		A	A	A
Wellness	2		*		A	A	A
Functioning	2						
Illness self-management	2		*		A		
Individualized service plan goals met							
Income	4						
Entitlements	4						
Other (please specify)							
Attendance and academic achievement on standardized tests	3 *				C		
Self-care or personal responsibility for wellness (rather than illness self-management)							
Self-advocacy							
Treated with respect							
Supported to make informed choices							
Diversity of management decision-makers							
Reduction in use of medications							
Hours of provider alternative medical training (% of same)							

Column 1	Column 2				Column 3		
Outcome and Performance Areas *Please note: The Children and Youth group noted the domain relevant to each area. The domain numbers are identified below after Attachment 7. The letters in the Level of Measurement columns refer to the age group which listed it.*	**Age Group** *** = Highest Priority**				**Level of Measurement**		
	Children and Youth (C)	**Transition-Age Youth (T)**	**Adults (A)**	**Older Adults (O)**	**Individual Client**	**Mental Health System**	**Public /Community Impact**
Functioning at highest cognitive level							
Reduction in APS involvement							
Linkage and access to primary care							
Life satisfaction							
Reduction in conservatorships and guardianships							

Attachment 7 – Form 2: Methods of Measurement

After each small discussion group completed Attachment 6, they next identified the type of measurement that would best capture the information, provided a short description of it, and suggested how often measurement should occur.

Outcome and Performance Areas	Type of Measurement						Provide a short definition or description of the measure	How often should measurement take place?
	Electronic Record	*Key Event Tracking*	*Survey/Standard Tool*	*Chart Review*	*Special Study*	*Database Linking*		
Transition-Age Youth								
Employment		X					AB 2034 status	Event triggered
Education		X					AB 2034/YSS Survey	Event triggered/ survey
Network of Supportive Relationships			X				Level of social support scale	6 months
Appropriate housing			X				Status change	Event triggered
Reduction in incarceration		X					AB 2034 status	Event triggered
Adults								
Reduction in homelessness		X					Range from homeless to independent housing	Monthly
Reduction in incarceration in jails						X	# bookings; # days incarcerated. Match jail and mental health data	Monthly
Reduction in institutionalization						X	IMD clients and days	Monthly
Reduction in hospitalization (long term care)	X						County billing databases	Monthly
Acute hospitalization	X						County billing databases	Monthly
Wellness and recovery			X				CA-QOL/Wellness and 12 Steps evaluation	Semi-annually
Meaningful use of time, including employment			X				Survey would be part of a guided interview	No consensus

Outcome and Performance Areas	Type of Measurement						Provide a short definition or description of the measure	How often should measurement take place?
	Electronic Record	*Key Event Tracking*	*Survey/Standard Tool*	*Chart Review*	*Special Study*	*Database Linking*		
Housing (adequate and safe)		X					Team (i.e. AB 2034) collects data	Key event
Health	X			X		X	Specific relating to being healthy (may be related to primary care system)	Per contact
Recovery and Wellness		X	X				Self-report in structured interview	Key event tracking, per contact
Older Adults								
Meaningfulness/purpose in life			X				Life satisfaction measure	Baseline, every 6 months
Network of supportive relationships			X				# of supportive contacts in the past week or # of people in network; 2) how person feels about quality of contacts	Baseline, every 6 months
Reduction in unnecessary and inappropriate institutionalization	X	X					# of days and # of stays. Can this be gathered from CSI? If not then electronic record and key event tracking	Real time, event triggered
Physical health and linkage to medical care				X			Use subjective: “In general, would you say your health is…?” To track linkage: chart reviews: have they seen a primary care physician?	

Small Group Discussion: Additional Information about Children and Youth

As described briefly above, the group working on children revamped the above exercise, and omitted Attachment 7. They identified life domains that have emerged over time from child-serving system work, and in particular through Children's System of Care (CSOC) experience. These domains relate to five basic overarching goals: all children should be:

- Healthy and happy
- At home
- In school
- Out of trouble
- Safe

The group advocated that these goals and the corresponding domains outlined below pertain to society's desired outcomes for all children, including those who experience mental illness and serious emotional disturbance. This perspective sets a context of wellness and resiliency for determining the best outcome indicators for children who receive mental health services.

The group advocated for a conceptual model that outlines five "quality of life" domains that may be affected by serious emotional disturbance and mental illness in children (and for all across the lifespan in their opinion). The best and most meaningful outcome indicators and specific measures that fall within each domain can then be identified by stakeholders. The proposed domains are:

1. Health and well-being: includes physical and developmental health, subjective experience of emotional and psychological health and personal behaviors such as alcohol and other substance use. Wellness, resiliency and recovery measures might fall in this domain.

2. Home, family and social network: includes aspects of life related to basic social needs which include nurturing primary caregivers, stable living situation, and involvement in developmentally appropriate socialization and recreation.

3. School: includes the acquisition of developmentally appropriate knowledge and skill development, usually within an appropriate school environment, that readies children for meaningful and self-sustaining work and/or activities, regardless of special needs.

4. Out of trouble: includes how children acquire and engage in pro-social behavior in all of the other domains; and how children develop effective behaviors that protect them from harming others or themselves and protect them from being at risk of involvement in the juvenile and adult justice systems;

5. Safety: refers to the area of life, particularly in children, that assures safety from harm from others and from the physical and social environment.

The group requested that selected outcome measures be understandable and practical. They recommended adding drop-out and school attendance rates, however, they were not comfortable with evaluating the provided indicators as the best ones for each domain for children and youth as this was seen as a secondary process to come after agreement on the five domains. They further noted the importance of other aspects of "meaningful use of time and abilities" beyond school, without negating school as fundamental in the developmental life of children.

Functioning, wellness and recovery, while considered important concepts, were perceived as too vague. The indicators must reflect resiliency and protective factors relative to the child thriving and achieving optimal development. Timeliness is a process or system measure, not a client measure. They recommended that DMH research existing indicators and measurement tools that have been validated, focusing on children who are thriving.

D. Technical Discussion of IT

Participants interested in discussing the technical aspects of IT met with DMH staff and consultants to focus on questions and answers. The participants chose to ask questions and make comments rather than hear a further presentation about IT.

Phase-In Process and Timeline

- Do not require inputting until the means of accessing data is available. When data are entered and disappear down a hole, it is extremely difficult to obtain buy-in. Do not require participation in inputting until DMH is prepared to allow counties to get data back.
  - **DMH Response (Gary Renslo (GR)):** DMH plans to make data and reports available to stakeholders in shorter turn-around time frames.
- Some county boards of supervisors have finally approved adoption of IT systems after years of negotiating. What kind of direction is DMH providing? Will the Department encourage counties to stop that process or will this system be adaptable with whatever they are doing? If they want new money, will they have to conform?
  - **DMH Response (GR):** DMH requirements will relate to system standards (e.g., it should have data transfer and security standards, data definition or schema standards, etc.). There will be flexibility. DMH recognizes the difficulties in planning and will work with each county in this IT transition.
- Does DMH have recommendations for system requirements to prepare for implementation? What is the timeline? What can counties do right now to gear up?
  - **DMH Response (GR):** Detailed requirements are not yet available; they will be developed over the next few months. DMH anticipates building a prototype schema. The Performance Measurement Committee and the IT workgroup will be working on their respective issues and will be collaborating to develop prototypes and tools.

- Is it possible for DMH to play a consulting and coordinating role between vendors and counties? Some counties have old legacy systems and deal with one vendor. Modifications are costly. This system may be pushed out to provider programs. Will counties obtain help figuring this out?
  - **DMH Response (GR):** DMH plans to collaborate with counties and vendors. While DMH may not fulfill a full consulting role, the Department does anticipate being available to counties to help think through modifications.
- If Los Angeles County does it wrong, it will have implications for everyone else. There will be back and forth about what can be done now before purchasing a new system and efforts made to explore which fields can be integrated, and which are not currently able to be adapted. Will counties be expected to make an archaic system work, and on what timeline? Will DMH be able to live with county gaps in information until it is clear what the Department will need? Los Angeles County is dealing with 30-year-old technology. Requirements do not sound like a phase-in, but rigid requirements.
  - **DMH Response (Carol Hood (CH)):** Even what DIG is requiring will change. Requirements are going to keep changing. It is a frightening thought from a programming and business process perspective. DMH needs to focus on development of a flexible approach that will be adaptable. It is not illogical to assume that there is some overlap between where a county is now and where it is going. It is possible to start working, in partnership, in order to develop a forward engineering design. Accountability does press the "I can give it to you in three years" approach. The expectation is that accountability will be a priority from the beginning. DMH will need to see progress toward eliminating static systems and developing more adaptable approaches. DMH hopes to help counties to discover ways to bridge the challenges in a step-wise process.
- Data without integrity is useless. Will there be clear rules about consistency and collection standardization? Business rules need to be in place before counties are required to collect information for a January 1, 2006 deadline. Is DMH's plan to publish requirements in September 2005 with a three-month turn-around on capture by January 2006?
  - **DMH Response (TR):** DMH will have a schema in time for the deadline. Each county will have to work with DMH on what is possible and what their alternatives are. January 1, 2006 is for those counties with CSS plan approval, who will be starting services in January 2006. This will probably be a small subset of counties.
- How much time would DMH give counties to implement XML application and provide data?
  - **DMH Response (CH):** Once services begin, DMH wants accountability from the beginning. For the Full Service Partnership clients, the process must be in place whenever services begin. New versions will be rolled out and requirements will increase over time. There will be another draft of Performance Measures in September. Counties will need to be responsive to changes. Think about the AB 2034 process: for every service element, think about the change process and accountability. DMH recognizes that this is a challenging process.

Consumer and Family Member Input

- Regarding consumer input into their medical chart: given how overburdened psychiatrists are already, is it even possible to consider client access? Is it really on the table? What is envisioned for consumers' involvement in data and for a feedback loop back to consumers? Will these data be available for providers to give back to consumers? Is it possible to filter and extract data that consumers would like?
  - **DMH Response (KK):** The model is to receive data from its owners, process it, and give it back to the original owner. The goal is to make data available while managing data access. Almost everything discussed today is technologically very doable. But the rest needs to be addressed in business practices and law. Requirements will need to be prioritized and phased in. Establishing standardization across counties is extremely important.
- Getting input from clients is not really driving implementation at the moment. People love to see their information real-time. Creating an integrated system is challenging given the range of places data are coming from. Is it reasonable that CSI/DIG/MHSA all be inputted in an integrated way?
  - **DMH Response (GR):** DMH is hopeful that all this could be done simultaneously.
- How is DMH interpreting the consumer/family-driven MHSA requirement in terms of IT? Hopefully, the powers behind HIPAA will not stop progress, but will wait and respond to implementation decisions.
  - **DMH Response (GR):** DMH has not yet seen any ways in which the proposals violate HIPAA. Prior to HIPAA, the issue of privacy was less clear and uniform. HIPAA is actually showing some benefit in this arena, although it has taken some time to implement HIPAA. HIPAA will help to improve portability and to maintain security.
- When designing screens, make sure they are flexible and provide opportunity to change language (e.g. changing "patient" to "client") and that the language used is non-stigmatizing and emphasizes recovery.
- How many consumers are in the IT and performance measure workgroups? Without their input, how will the design of the system be consumer-driven? Consumer participation in design, implementation and quality assessment must be in the county and state requirements.
  - **DMH Response (GR):** There will be consumers and family members on these groups.
- Often information, such as race and ethnicity, is inputted incorrectly. Consumers should be able to review the file and correct information.

Coordination and Integration

- Coordinate CSS and IT.
- What happens to CSI reporting when the new system starts? Will MHSA reporting just be for new clients? Should county systems build a CSI interface or not?
  - **DMH Response (TR):** CSI data could eventually come in through a new portal. The portal will support multiple methods of receiving information. It should not matter what the source of the information is. The goal of a standard interface is

to allow a stream of input for different types of data. CSI information will ultimately be a part of that.

- There should be someone with IT expertise on the Performance Measurement Committee. Is there a requirement to have someone who can talk IT implementation? Is DMH committed to reducing redundancy?
  - **DMH Response (GR):** Clearly, it would be a good idea to have IT well represented in the performance measurement discussions and the two sections at DMH are in close communication. The CMHDA IT Committee is very committed to using IT to eliminate redundant reporting.
- Cost reporting data should also be integrated in this conversation.
  - **DMH Response (GR):** Yes, DMH recognizes the importance of this integration.

Provider Issues

- When will the definition files be ready? How soon will counties be expected to input? DMH should take leadership on expectations regarding how counties will implement IT and that they will implement it consistently. Private providers need to be able to access; it would be useful for counties to take XML data directly from providers. DMH should indicate: "This is how you will communicate" and expand out to providers.
  - **DMH Response (GR):** The schemas will be defined over the next few months. Counties will be expected to input data when they begin services and supports delivery. DMH is planning on setting infrastructure standards, and county, provider and state transfer and exchange of information is one of the issues that will be addressed with each county.
- Most of the talk so far is directed at counties submitting data to DMH. Many provider agencies do not currently provide any information to the counties. It would be easier for provider agencies to input data directly to the State.
  - **DMH Response (GR):** The State receiving data directly from providers would seem to be a paradigm shift on the part of the counties. One technical alternative might be to pass provider data through county staging databases and then on to the State.
  - **DMH Response (CH):** DMH's relationship is with the counties. It is the county that contracts with providers.
- Will extractions be allowed at the county level only or also at the provider level? MHSA monies are not supposed to be used to replace current systems, but what is the reality of that? Counties have not moved forward because of funding inadequacies.
  - **DMH Response (TR):** The issue of provider versus county submission of data will need to be explored further. The goal is not to replace dysfunctional billing systems, but rather to transform the system. The beginning will be a statewide schema.
  - **DMH Response (CH):** To clarify: no consensus has yet been made about the extent to which MHSA should pay for these things. Counties needed basic functionality prior to MHSA. Transformation funding should not be used to replace existing systems.

- What is the process of batch vs. real-time XML? Will counties have the option for batch XML transactions? How will providers input data? Following input, is data sent immediately back to contract providers, county, DMH? Is that the vision of the future?
  - **DMH Response (TR):** The general idea is not to take over what counties are doing, but to provide standard ways to talk back and forth, and to encourage as much real-time conversation as possible. As long as the data meets standards, it is possible to program in triggers and events to automate updates. This is currently happening in state hospital systems: when updates occur in one place, changes are sent out immediately. It is fast, if not immediate.
  - **DMH Response (CH):** While it is possible that provider data might come directly to DMH, it may not necessarily be the case. For instance, the Medi-Cal approval process would still need to be in place.
- Will providers be included in bi-weekly workgroup meetings?
  - **DMH Response (GR):** This workgroup will be the CMHDA IT sub-workgroup for the MHSA. It will be similar to the Collaborative HIPAA Implementation Project (CHIP) workgroup. The workgroup will include provider members.

Formatting, Software and Hardware Issues

- Are we talking about a web page, read-only form where the data goes into a server database, is stored, comes out of that database, and goes back through to the counties?
  - **DMH Response (KK):** That is one option. It gives the counties an opportunity to change portal approaches. The web page is one model that will be posted and made available. DMH will find out from counties what approaches are desirable.
- DMH needs to specify a standardized collection procedure.
  - **DMH Response (TR):** DMH will be working with each county and their vendors to determine the best method for data transfer. There will not be one single way. DMH is looking at several designs.
- How is DMH working with the federal process on nationalizing medical charting and SAMHSA? Is DMH re-inventing the wheel or will California be using these processes? "Interoperability" is being used a lot lately. Is it a new concept? Is it really technically feasible given the level of incompatibility?
  - **DMH Response (GR):** California will definitely be in the lead. Dr. Brailer's office has put out a Request for Information (RFI) for interoperability. The vision over the next ten years is on how to interconnect systems so they can successfully share information. SAMHSA is also looking at how to improve communication about IT process change.
  - **DMH Response (KK):** Interoperability is feasible over time, once consensus is established about what data elements are critical and there is shared understanding of values regarding data elements. The term "inter-operability" has been around for a long time. It is an engineering principle. The idea is to build systems from discrete components that are designed to perform small, specialized tasks. You combine the components by attaching their interfaces to solve a bigger piece of the puzzle. These engineering principles have been around for a very long time, in other engineering sciences such as electrical and

civil engineering. They are all around us: for example, your DVD player may be made in Japan by Sony, while your TV is RCA made in the USA. You do not need to care about the internal wiring of them as long as they all work together. Computer science is now advanced enough to apply the same principles to software and computer systems.

- What are the back-end requirements? Compact super computer? Does DMH anticipate problems with processing?
  - **DMH Response (GR):** DMH has not yet created the detailed MHSA back-end design, but does have a sufficient supporting infrastructure. For example, DMH has fiber optic connectivity to the Health and Human Services Data Center, which in turn has T3 connectivity to the Internet. Both DMH and the data center have firewalls to protect against intrusion. All data transfers with counties are encrypted via SSL. DMH uses a multi-tiered server model so that protected data does not reside on authenticating servers and applications for production or test environments. DMH's servers can currently process a million records in an hour. DMH can accept the additional required MHSA data, and these processes will not overtax the current infrastructure.

Funding Timelines

- What is the timeframe on a decision regarding what dollars can be used for what projects? What is the funding timeline?
  - **DMH Response (GR):** DMH will specify short-term requirements and will require fully integrated and interoperable electronic medical records as a long-term goal. Depending on the county, the short-term IT system changes may not be that extensive or expensive. However, the long-term IT transition will be expensive. DMH will work with each county to determine their approach and funding requirements for phasing in the electronic medical records system.
  - **DMH Response (CH):** September is the earliest timeframe for draft initial funding plan requirements for IT allocations. No decision has yet been made about funding for Capital Facilities vs. IT. MHSA does not specify. DMH is also not sure how much short-term funding will be available. Clearly, information is critical to move forward on decision-making. DMH is awaiting the supplantation decision any day. July 7 is the first meeting of the MHSA Oversight and Accountability Commission.
- The performance measurement process is underway. What is the context and timeframe for the Performance Measurement Committee?
  - **DMH Response (GR):** The Performance Measurement Committee nominations are due June 30. It will take several weeks to determine committee members and for the committee to convene. The Performance Measurement Committee will work on indicators and data elements in a parallel process with DMH's CMHDA IT subcommittee's work on standards setting and system design. The CMHDA IT subcommittee meets monthly. In about three weeks, the members of this committee, stakeholders, vendors and providers will form an MHSA IT workgroup that will meet every two to three weeks. DMH and the MHSA IT workgroup will work together to set the initial IT standards and design for the

short- and long-term timelines and to figure out how to transition from point A to point B.

- What does “final” mean vis-à-vis performance measures? Will it be before January 2006?
  - **DMH Response (GR):** The quantity and definition of data elements depend on the stakeholder and Performance Measurement Committee processes. It will be an iterative process and is being addressed within a quality improvement framework. Data elements will be defined prior to January that will need to be supported by the short-term IT requirements (discussed previously). The concept of “final” could be a misleading way to describe the performance measures, as they will change over time as progress is made toward the transformation reflected in the MHSA.

Real-Time Exchange

- Has DMH considered multi-core processing, which enables a greater ability to handle multiple tasks in real-time?
  - **DMH Response (GR):** DMH is currently using servers with multiple processors for its larger database systems.
- It is likely that different information streams will have different processes. DMH might still get information for statistical purposes, but cost information goes also to Medi-Cal for approval. If it is done right, it has tremendous implications for fixing data problems, to the extent entry problems are evident in real-time.
  - **DMH Response (TR):** Yes. The schema requirement for “well-formed” data can help with this by providing immediate error feedback.
- Los Angeles County has caused problems in the past because of the volume of data generated. Is DMH gearing for large counties or for a normal county? Will small counties get lost in the processing of a large county submission? Would DMH get inundated and stop timely processing of smaller county submissions?
  - **DMH Response (GR):** DMH will base its development on statewide needs. Both large counties, like Los Angeles, and small counties will have timely processing of data.
- How will counties and agencies be able to input data during down-time so that the entire state is not down?
  - **DMH Response (TR):** As far as “down-time,” many large companies are 24/7. For example, Delta Airlines does not shut their systems down. There is a capability to image a system and run off that image during maintenance and fix times. These are part of DMH’s IT discussions.

XML Issues

- Is XML a dictionary? Is it a program? How will information transfer occur? Can it be speech-recognizable? How secure is the system?
  - **DMH Response (KK):** XML schema is a structure within which data relationships can be defined. It is adaptable. Based on protocol, information could be shared. Adapters need to be in place to transfer information. The XML paradigm includes an automatic adapter that can read XM- defined “well-formed documents.” There are many different ways to set up firewalls and security

socket layers to make sure there are no corruptions and reduce the risk of intrusions. It uses "component-based engineering" programs for discrete approaches to events and situations, instead of top-down programming.

- Can one take information from another entity and load it to XML? When no electronic transfer is available, can XML be used for scanned paper data?
  - **DMH Response KK):** Yes. Plug-ins are available. Data transfer and interoperability are via XML, but data capture can be done via county systems. Interface is standardized, but the infrastructure does not need to be. The Board of Equalization and Franchise Tax Board use XML. The process is similar to going into a browser for a website and having whatever is necessary load automatically. For more information, try a Google search: "XSLT-FO."

For additional help with definitions or explanations about any of the terms discussed today, check out the web definition page: www.whatis.com.